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Nurse involvement in analysis-based decision support in the clinical context

Mette Kjer Kaltoft, Jack Dowie

Ailsa Hart, Marian O'Connor, Christine Norton

Outline: menu

- Introduction: the research project
 - Clinical setting: St Mark's Hospital, London IBD Clinic
 - IBD: Impact of chronic diseases (Crohn's and Colitis)
 - Decision aid: Multi-Criteria Decision Analysis (MCDA)-based *MyCrohn'sAL*
- Design: customisation and personalisation
- Delivery: intervention (baseline precedes)
(numbers shown should not be used without contacting us)
- The future: implications and developments

What's the matter?



What matters?



What might be lost?



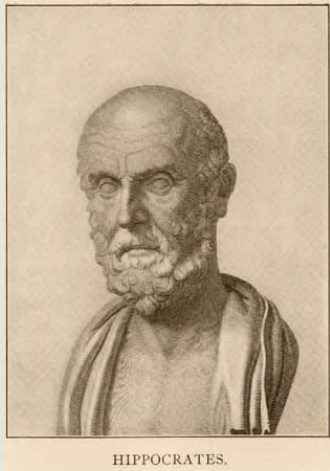
IBD: Inflammatory Bowel Disease

- WHY? Interaction between our genetics, our immune system and our environment
- WHAT? Illness can be kept under control with medication, but despite extensive research, there is no known cause or cure for IBD today
- WHO? **Impact** Europe 2.2 million (5m globally)
- 2011 Survey by 26 IBD Patient Associations... 66% reported negative overall impact on quality of life..... 22% that IBD has been a reason for ending an intimate relationship
- Multiple criteria; New technologies; Costs

Open Information Day
Patients with IBD
IBD Specialist Nurse team



Once upon a time: (r)E-volution of the E-Patient



Hippocrates c400 BC

“perform your duties calmly and adroitly, concealing most things from the patient while attending to him... revealing nothing of the patient’s future or present condition”

“NOTHING ABOUT ME, WITH ME”



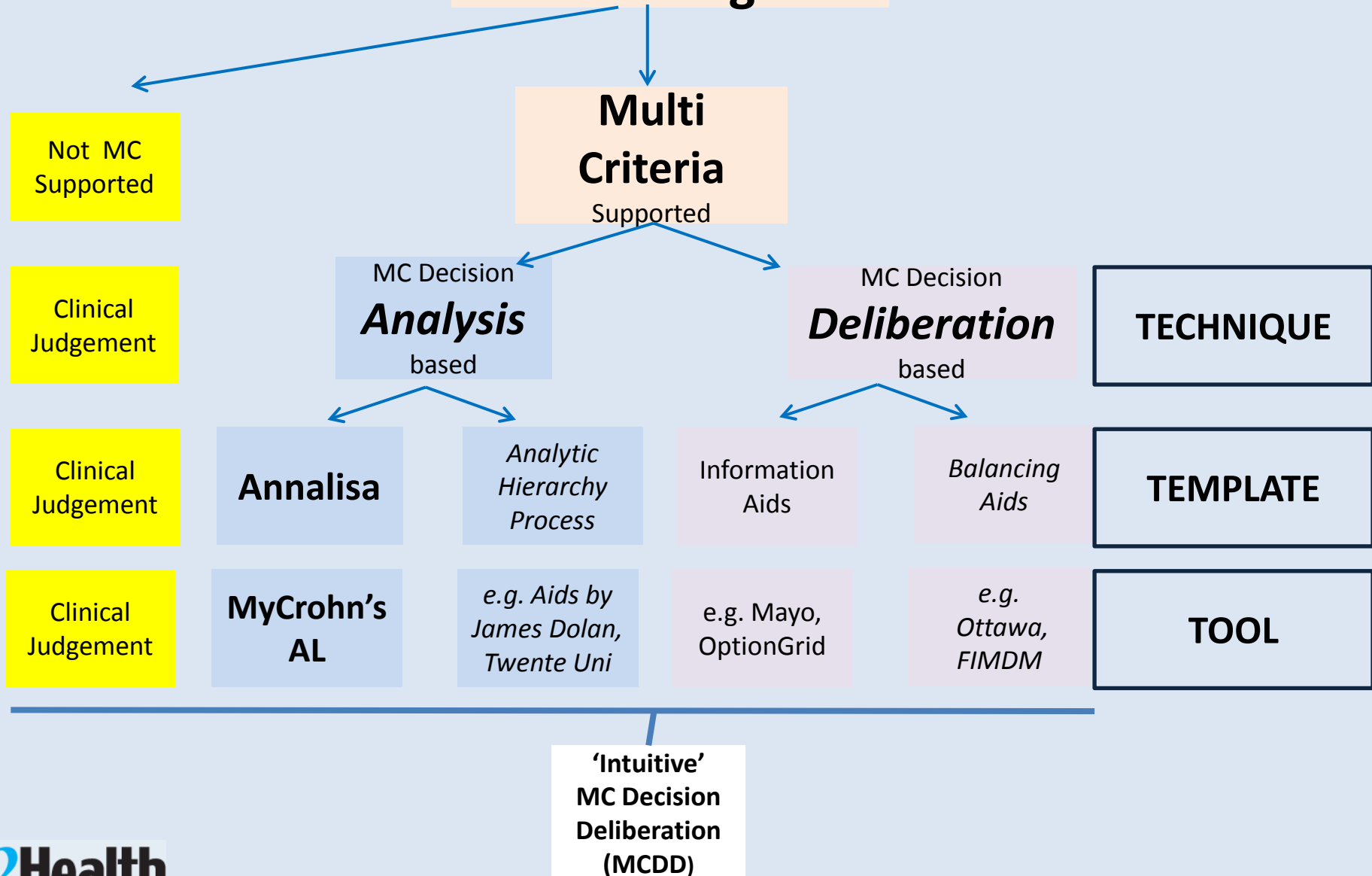
Donald Berwick 2009

“NOTHING ABOUT ME, WITHOUT ME”

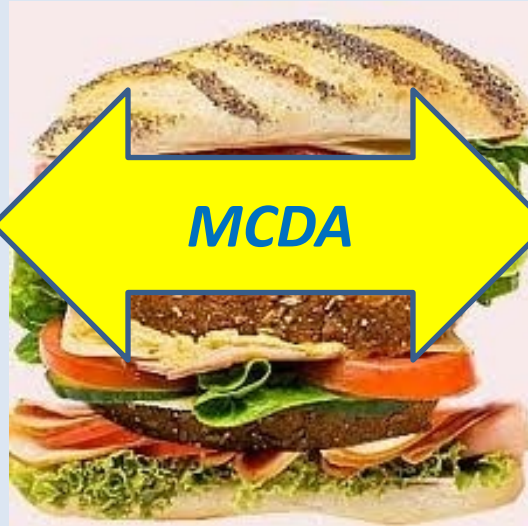
Obama Health Care Act 2010

mandates aids for shared decision making

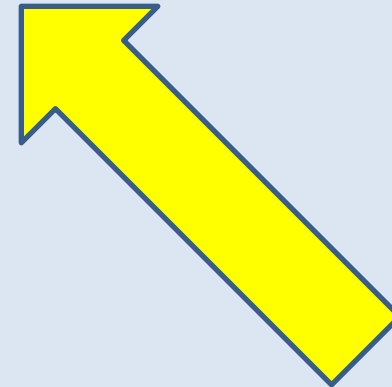
Clinical Decision Technologies



Decision



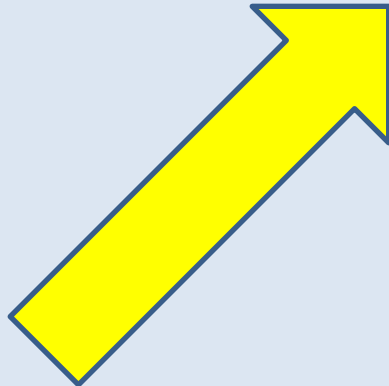
Sandwich



Values



Filling



Evidence

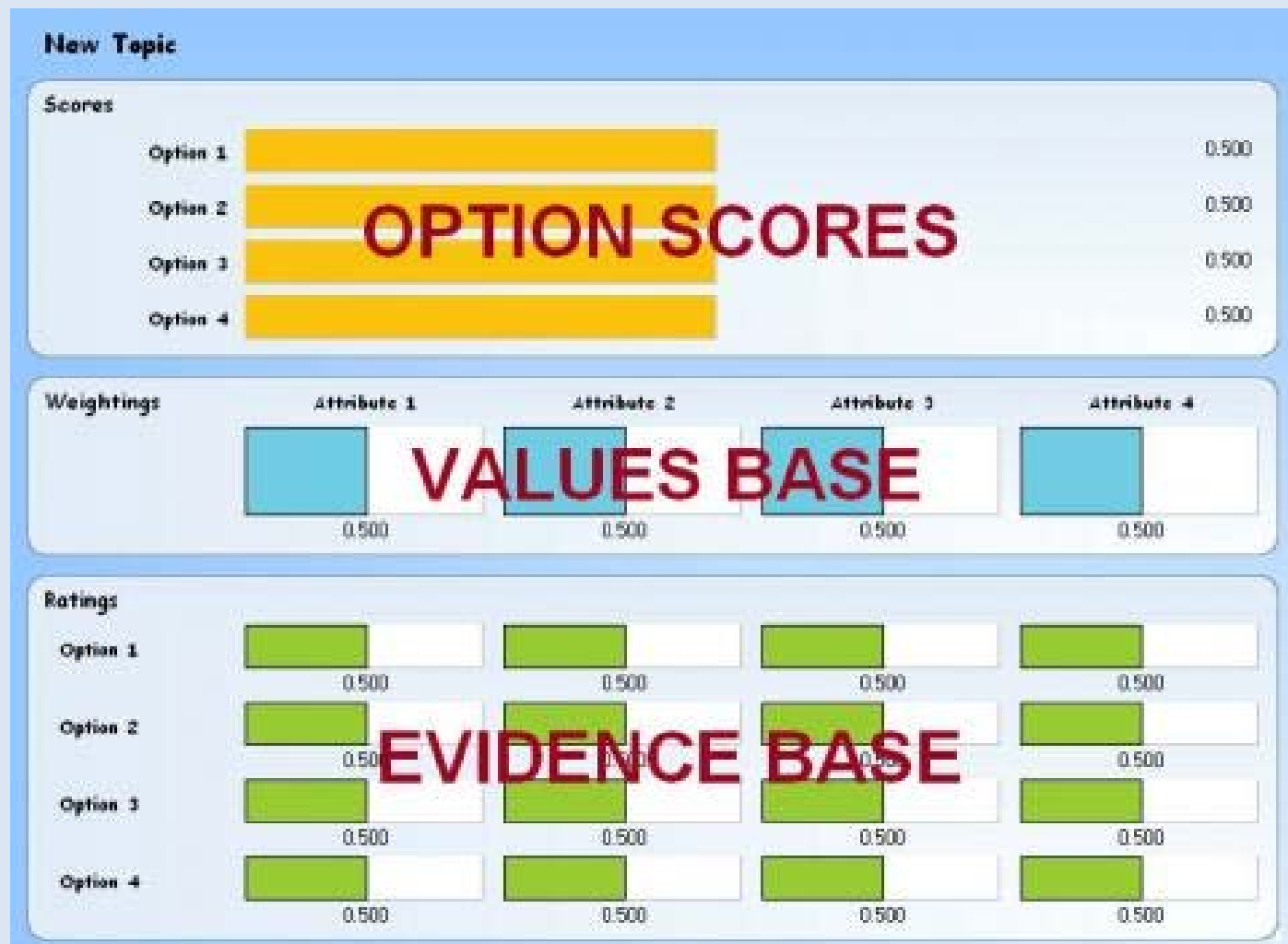


Bread

Multi-purpose

- **Support** for up-to-date shared decision making
- **Documentation** using the decision support template MyDecisionSuite: MDS within which the decision aid is embedded (file can be saved, exported and printed)
- **Evaluation** of the decision using the MyDecisionQuality (MDQ) element of MDS

One screen fits all... and all



THE ANNALISA FRAMEWORK

Attributes to be weighted (valued)

- Disease severity
 - [Remission]
 - Clinical Remission without Mucosal Healing
 - Mucosal Healing without Clinical Remission
 - Moderate Disease
 - Severe Disease
- Side effects and Adverse events
- Treatment burden; impact on life / relationships

Options to be rated

- No change
- Thiopurine
- Anti-TNF biologics
 - Infliximab
 - Adalimumab
- Combination
- *Surgery (Ulcerative Colitis aid)*

Rating the options with BEANs: (Best Estimates Available Now)



- Evidence-based ratings: in this case no relevant Meta-Analysis or Network Meta-Analysis available
- Expertise-based ratings (E-Delphi process): for Disease severity stages, Side effects, and Adverse events
- Patient-based ratings: for Treatment burden; Impact on life / relationships

Patient with IBD nurse and *MyCrohn'sAL*



using the 'save for later' function creates unique ID



Patient with consultant

Consultant re-opens for final decision to be made in light of *MyCrohn'sAL* opinion



My Decision Suite (MDS)

My Decision Navigator (MDN)

Customises route through remaining elements of MDS on basis of constraints, competencies and preferences

My Decision Preparation (MDP)
includes My Decision Quality (pre)

Information on options and attributes in MDA; Elicits weights for 8 MDQ items

My Decision Aid (MDA)

Elicits personalising modifiers for AL ratings; presents AL with Scores and ratings and Sources if requested

Records decision (maybe deferral or probabilistic) + relation to AL scores

My Decision (MD)

Elicits ratings for MD+ on 8 MDQ items; allows re-weighting; presents MDQ score + breakdown to facilitate DQ improvement

My Decision Quality (MDQ) (post)

Establishes what is agreed to be done (monitoring, behaviour, outcomes) and timing, in all relevant settings

My Decision Follow-up (MDF)

Annalisa (AL)

Elicia (EL)

MyDecisionQuality (to elicit weightings pre decision)

OPTIONS

Importance of being clear about the possible OPTIONS for me and the process they involve

EFFECTS

Importance of being clear about the possible EFFECTS and outcomes of each option for me

IMPORTANCE

Importance of being clear about the relative IMPORTANCE of the different possible effects and outcomes for me

CHANCES

Importance of being clear about the CHANCES of the different effects and outcomes happening to me, including the uncertainties surrounding the best estimates of them

TRUST

Importance of being able to TRUST the information I was given was the best possible

SUPPORT

Importance of feeling I received the level of SUPPORT and consideration I wanted throughout the decision process, especially in regard to communicating at my level

CONTROL

Importance of feeling I was in CONTROL of my decision to the extent I wished

COMMITMENT

Importance of feeling COMMITTED to acting on the decision taken



The Future

- New Settings
 - Online survey using MDQ (Danish research: OUH Svendborg Sygehus and IBD association www.ccf.dk)
 - Direct consultant delivery in clinic (Sydney research)
 - E- and M- Patients preparing for consultation
 - Open access through Patient association websites
- Common decision picture and language used to facilitate communication and translation across all healthcare settings and disciplines
- Concordant decision making, informed choice and 'perfected' informed consent for the EMR

TranslationAL E-Health & Concordance

HCDUCK CLIPS2 - BY ANNALISA

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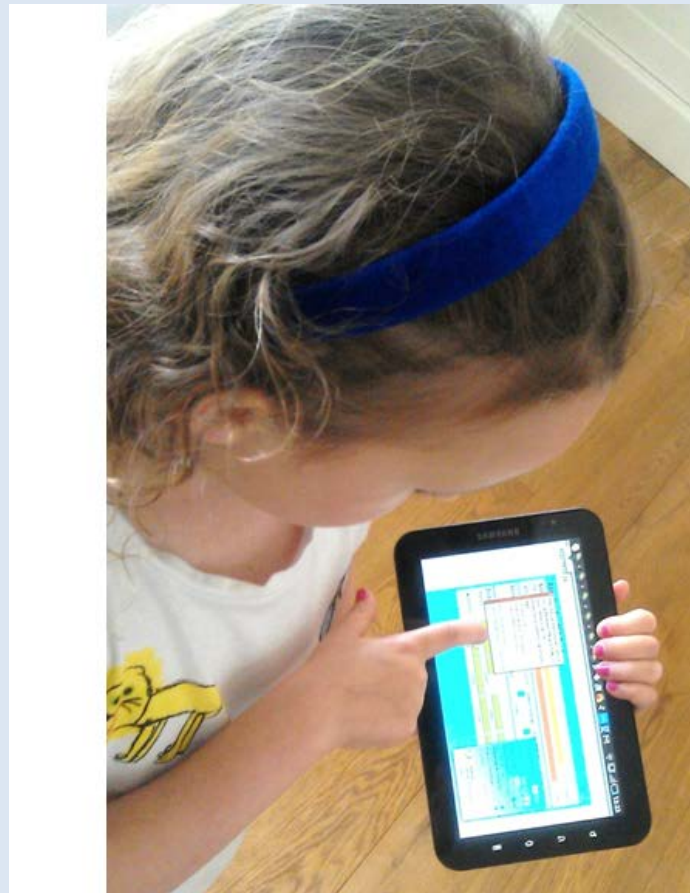


Florence Nightingale today?

Technology Informatics Guiding Education Reform



Thanks for attending



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Questions or comments? Please, e-mail
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